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ABSTRACT

The purpose of the Children's Project in Oregon was to provide services to five children (ages 5 to 12) with developmental disabilities whose families were experiencing stress. Each of the children had at least three disabilities and was placed outside the family home in a foster care home for various reasons. The project staff included each child's case manager, the home provider, a parent trainer, the child's natural parents, and an administrator. Results of the project indicated that the children acquired self-help skills. Benefits and limitations of the project are discussed. (Author/DB)

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# The Children's Project: A Residential Option for Children with Developmental Disabilities

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*Abstract*

*The purpose of the Children's Project in Oregon was to provide services to five children with developmental disabilities whose families were experiencing stress. Each of the children, aged five to 12 years of age, had at least three disabilities and were placed outside their family homes for various reasons. The project staff included each child's case manager, a home provider, a parent trainer, the child's natural parents and an administrator. Results of the project indicated that the children acquired self-help skills. Benefits and limitations of the project are discussed.*

## Background

What prompts a family to request out-of-home placement for a child with disabilities? Studies indicate that increased levels of family stress may be a factor (Blacher, 1984; Crnic, Friedrich, & Greenberg, 1983; Gallagher, Beckman, & Cross, 1983).

Factors contributing to placements are of two types, those related to the child and those related to the family. Some factors related to the child are the child's age (more requests are made for older children), number of diagnostic disabilities, and behavior problems. Family factors contributing to placement include disruption of family relations, family mental health and/or health problems, and lack of social support and services for families and the child (Seltzer and Krauss, 1984; Tausig, 1985).

Research indicates a need for increasing the family's coping ability in order to lessen the stress of caring for a child with disabilities and suggests doing this by increasing support to the family. The greater support the family has, the better it is able to cope with the stress of raising a child with handicaps (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Crnic et al., 1983; Friedrich, Wilturner, & Cohen, 1985; Geist & Baer, 1980; German & Maisto, 1982; Intagliata & Doyle, 1984).

In Oregon, out-of-home placement is one of the few options available to families experiencing stress who have children with developmental disabilities.

According to the Oregon State Children's Services Division, 352 children with suspected or verified handicapping conditions are in out-of-home placements in Oregon. Eighty-eight percent were under the age

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of 13 at the time of placement. Eighty-three children have been placed in the state institution over the past three years.

Minimal state funding is available in Oregon to assist families with children three years of age or older who have developmental disabilities. Unless parents request continuation, mandatory case management services end when a child enters school until age 15.

The purpose of the Children's Project was to provide a residential option in the community for children with disabilities to foster the ties between the family and child. Parents who placed their child did so with the intention of maintaining the child in the project until the problems which prompted placement were remediated. Alternatively, some parents placed their child with no intention of having the child reenter the family home.

## Participants

The Children's Project served children five to 12 years of age who had developmental disabilities. Two of the children in the project were living out of their parents' homes in an institution when the project began. Three of the children were placed in the project by their families.

Children in the project were placed outside their family homes for many of the same reasons indicated by other research (Seltzer & Kraus, 1984; Tausig, 1985). For example, in two cases, behavior problems were cited as the reason the children were placed. In a third instance, the family had more than one child with developmental disabilities for whom to care. In the fourth case, the parents' physical disabilities did not permit them to care for their child. In the fifth case, the child referred to the project had extreme care needs and the nature of the child's disabilities prompted placement. Four of the families were raising two or more other children ages 12 or under.

Table 1 depicts factors cited as contributing to out-of-home placement of children and the percentage found to be related to project participants.

Children in the project ranged from being moderately disabled to profoundly disabled and had a wide range of disabilities. All children had three or more disabilities.

Table 2 displays seven disability characteristics and the percentage found in children participating in the project.

## Methods

The Children's Project started in May 1986 as a means of assisting families under stress and their children.

The project differed from other children's residential programs in that the parents rather than the courts initiated placement of the child

Table 1
Factors Found in the Literature to Contribute to Out-of-Home Placement and Relationship to Children Placed in Children's Project

| Factors contributing to placement | Percent children/families in project |
|---|---|
| 1. Number of diagnostic disabilities | 100% of children had 3 or more disabilities |
| 2. Behavior problems | 80% of children had behavior problems |
| 3. Health problems | 20% of families had parents with health problems |
| 4. Other children with disabilities | 20% of families had another child with disabilities |

Table 2
Seven Diagnostic Disability Characteristics and Percentages of Occurrence in Project Participants

| Types of Disability | Level of Disability | | | | | |
|---|---|---|---|---|---|---|
| **Disability** | **Profound** | **Severe** | **Moderate** | **Mild** | **Suspected** | **% Occurring in participants** |
| Autism | | | 1 | 2 | | 60% |
| Communication | 3 | | 1 | 1 | | 100% |
| Mobility | | 2 | | 2 | | 80% |
| Visual | | 1 | | | | 20% |
| Auditory | | | | 1 | | 20% |
| Mental Retardation | 2 | | 2 | | 1 | 80% |
| Behavior | | | 3 | 1 | | 80% |

and retained all legal rights for the child. They maintained close contact with the child throughout the placement.

Children were placed with families in the county where their parents resided. Project homes were selected jointly by the local mental health authority and project staff. Homes had to meet a combination of Oregon licensing requirements for adult foster homes and small intensive training homes. Parents interviewed prospective home providers to determine which family would best accommodate the needs of their child.

Project staff included each child's case manager, a home provider, a parent trainer, and the child's natural parents, as well as an administrator for the project.

The home provider's role was to provide direct care for each child as well as teaching practical living skills. The parent trainer's role was to train the home provider in teaching techniques, to design formal skills programs to use in teaching each child, and to monitored the teaching. The case manager monitored each child's general care to assure that State standards were being met through the project. The parents assisted in the design of their child's habilitation plan and were required to provide respite for home providers on at least a once-per-month basis. In most cases, parents had their children home on a much more frequent basis.

Parents continued involvement with their children to the degree to which they felt able. For example, some parents retained all responsibility for the child's medical care, clothing, and finances. Two children spent most weekends at home and lived with the providers' families during weekdays.

Supplemental Security Income provided the room and board payment for the child's out-of-home care at a rate of $299.70 per month per child. The State of Oregon contributed a service payment to the provider to pay for each child's training and other services the provider performed for the child. The service payment was about $400.00 per month.

The child's parent, home provider, the parent trainer, and local case manager designed an habilitation plan for each child which specified whether the parent or home provider would be responsible for the clothing, medical, and other needs of the child. Skills the child needed to learn were prioritized at this time and some skills were selected for training.

Home providers spent an average of four hours per week teaching the child practical living skills with systematic techniques and documented the results of the teaching. The parent trainer worked with the home provider on a once-per-week basis.

Parent training services were also offered to the children's parents. Parents were not required to accept services but had this option available to them if and when they desired it. The parent trainer coordinated teaching programs between both homes when requested by natural parents and with the school the child attended, to provide continuity of programming for each child. The trainer was available to assist home providers, parents, and school personnel with behavior management issues as these arose.

Home providers were taught and encouraged to assist children to develop skills, not only through formal teaching, but also by using natural situations occurring within the environment, called informal training. Informal methods consisted of giving each child the assistance necessary to help him or her complete the task in which he or she was engaging rather than doing the task for the child. Unlike formal teaching, no written systematic methods were used and data was not recorded on an ongoing basis. Skills were assessed by the parent trainer once per year. Home providers documented new skills as they were acquired.

Behavior management techniques endorsed by the project consisted of setting firm guidelines for each child, teaching new positive behaviors to replace negative behaviors, and providing positive reinforcement for desirable behaviors.

Other therapy needs of the children such as speech, occupational and physical therapies, as well as counseling and special equipment were provided through local vendors and paid for by the project. If desired, families could receive counseling services paid for by the project.

Home providers and parents were offered ongoing training and education through the project, including workshops on topics such as epilepsy, behavior management, stress management, and others.

## Results

In the Children's Project, all children acquired skill in self-help areas such as bathing, dressing, and toileting, as well as in communication, recreation and leisure, and household responsibilities. Table 3 depicts the results of some formal skills programs during the first eight months of the project.

Children learned a number of skills through the informal teaching given by the home providers. Table 4 displays some of the skills learned by children through informal methods.

With the exception of one home provider, childrens' behavior problems did not transfer to the providers' homes. The problems were initially managed effectively by most providers and did not become unmanageable. All children continued behavior problems to some degree in their family homes during home visits.

Table 3
Some Skills Acquired Through Formal Data-Based Training
During First Eight Months of Project

| Data-Based Formal Training | | | |
|---|---|---|---|
| Skill | % Baseline | % Last review | Months with training |
| Bathing self | 0% independent | 68% independent | 7 |
| Washing hair | 0% independent | 75% independent | 7 |
| Dressing self | 12% independent | 80% independent | 5 |
| Responds to verbal cue—toileting and washing hands | 6% independent | 61% independent | 8 |
| Table manners | 41% independent | 75% independent | 4 |

Table 4
Some Skills Acquired by Project Participants Through Informal
Training During First Eight Months of Project

1. Dresses self
2. Puts clothes in hamper
3. Eats at dining room table with family
4. Plays with nonhandicapped peers
5. Rides 3-wheel bike
6 Signs "eat"/"drink" for food
7. Eats independently with fork and spoon
8. Holds toys
9. Waves "hi"/"bye"
10. Responds to signs "finished," "stand-up," "come," and "wait"
11. Hangs up own coat
12. Puts toys away
13. Crawls rather than swims for general mobility
14. Takes steps independently when supported by others

To date, only one set of parents has consistently requested help from the parent trainer for behavior management issues. They had received help throughout most of the project. The parents in this case had learned to successfully manage their child's behavior problems in several settings. For example, they had learned to eliminate tantrums which occurred during shopping at the local grocery store, in the bathtub, and during car rides. They did this by clearly defining what behaviors were appropriate for the child to engage in, teaching their child these behaviors, and reinforcing the child for performing acceptable behaviours.

## Discussion

The Children's Project has improved the quality of life for five children who had developmental disabilities and their families. Benefits to children and their families are described below.

For two of the children living in the institution, the project provided them with a means to reenter the community and reside in a family environment. For one of these children, the project appears to have strengthened ties between the child and the natural family. The family visited the child on a more regular basis and participated in most decision-making related to the child including training and school programs as well as such items as hairstyle, clothing, and choice of medical personnel.

Natural parents received relief from providing 24-hour care for a child who was difficult to manage in the home. Yet the natural parent retained all rights to the child and participated in most decision-making. Parents could have as much contact with their child as they desired.

The children in the project were provided with consistent teaching to develop practical living skills. All children had made progress in caring for themselves. The project was designed to provide continuity of programming between home and school environments when this was needed and/or requested.

For the children with behavior problems whose relationship with parents were disturbed because of these problems, the relationships became more positive. Parents who were unable to speak positively about their child when the child was placed, within a few months of placement, begin to appreciate the child again. This may have been due to a number of factors. First, the parent had an opportunity to witness another family and project personnel enjoy the child despite his or her limitations. Second, the parent was relieved from the stress of direct care for the child and managing the child's behaviors. Third, the child's behaviors and skills improved, changing the way in which the parent perceived the child and altered the relationship between them.

Despite the benefits of the project there were negative factors as well. The project was designed to maximize and maintain the relationship between parents and the child. Nevertheless, removing a child from his or her family home was a painful experience for both parties. The parents were able to understand the separation; the children could not. Both experienced depression and other signs of stress after placement.

Another criticism of the project came from a parent. The lack of services to families in Oregon made this project necessary. If families had been provided the same level of service and support that was available to project providers, removing the children from their homes might not have been necessary. Because of this, children who enter the project in the future will be served in their family homes with the goal of preventing out-of-home placement. Parents currently in the project who eventually move their children home will receive services from the project through a transition period to assure the success of the child's reentry.

The difficulty in recruiting and maintaining quality home providers for the children was another criticism of the project. The most successful placements occured when parents were solidly committed to maintaining the provider's home for their child and when the provider was dedicated to the welfare of the child thus committed to maintaining a harmonious and uncritical working relationship with the parent.

Good communication between the parents and home providers, and the intent to work cooperatively together were essential if a child was to have a stable placement. This meant that the home provider must be supportive and uncritical of the parent which was not always easy to do when the home provider was able to teach the child and control his behaviors when the parents could not.

Although parents wanted the best for their child, they often felt inadequate when faced with a home provider who could work effectively with their child. Parents experienced guilt for placing their child with another family and received criticism from members of extended families, from friends, and from acquaintances. Parents who were considering out-of-home placement needed to be counseled as to the feelings and situations they might experience.

Home providers sometimes felt a lack of control over the child because decision-making involved a team of people, with the parent ultimately having the most control over the child's care and training. Parents were also able to remove the child from the home and project at any time which is threatening to home providers.

Due to the degree of parental involvement, home providers sometimes felt less responsible for the child than did other providers such as foster parents and group home providers. Children may have been considered more *boarders* than actual members of the home provider's

family. Also, the home providers sometimes expected more from the natural family such as caring for the child during holidays and provider's family vacation and expected to provide less service to the child.

Thus, the project had negative as well as positive features. It was predicted that at least two of the five children in the project would return to their families. Two of the three remaining children would most likely continue living in residential settings different from that of their families. For all children, involvement with their natural families would most likely continue.

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